Executive Summary

The issue of providing uncompensated kidney disease care to all individuals living in the U.S. persists and continues to grow. This position paper discusses the characteristics of the citizen and non-citizen populations receiving uncompensated care, outlines the current status of public benefits available to these individuals on both the national and state level and explores the ethical issues these circumstances present to both nephrologists and dialysis facilities treating these patients.

The RPA believes that the federal government has a responsibility to provide care for all patients within the borders of the United States, and that the financial burden of uncompensated care provided to both citizens and non-citizens is both a federal and state responsibility. The RPA also believes that all health care professionals and health care systems have an ethical obligation to treat the sick, and that all citizens and non-citizens should be eligible for emergency Medicaid services if they do not have insurance coverage or resources to pay for dialysis.

Background

As the consequences of the profound federal budgetary restraint in the United States have continued to evolve in the early 21st century, many segments of society who are already somewhat financially disadvantaged have become increasingly marginalized, further increasing disparities in access to care. Among these at-risk populations are citizens who either cannot afford or choose not to have health insurance, and the nation’s non-citizen population, who for the purposes of this paper can include but not be limited to undocumented immigrants, minors born in the U.S. to undocumented immigrants, temporary workers, students on visas, and visitors. Legislative initiatives such as the Affordable Care Act (ACA) have sought to reduce both the number of uninsured individuals in the U.S. and the amount of uncompensated care provided. However, the fragmented implementation of the law has either limited its potential positive impact or has complicated efforts to provide care to at-risk populations. Furthermore, the ACA specifically excludes payment for the care of non-citizens.

For U.S. citizens and non-citizen patients with chronic kidney disease (CKD), including End-Stage Renal Disease (ESRD), this problematic scenario can have grave consequences. CKD is a silent disease with few discernible outward symptoms and in all likelihood disproportionately affects marginalized segments of society who do not receive preventive healthcare. As a result, these individuals with CKD would have a greater likelihood that their condition will progress more rapidly to ESRD. The primary treatment modalities for ESRD patients are dialysis or
transplantation. Dialysis is a therapy that is prescribed for those with irreversible kidney failure who must receive renal replacement therapy to survive, and is not an elective procedure for ESRD patients. Once diagnosed, most ESRD patients require dialysis several times a week, for around four hours per session typically in an outpatient setting, for the remainder of their lives, if they cannot receive a transplant. Therefore, for citizens and non-citizens with ESRD, difficult access to or denial of dialysis services will invariably hasten the patient’s demise and ultimate death.

Treatment of these uninsured patient populations results in significant financial hardship for dialysis facilities and hospitals, and could threaten their financial stability. The care of these patients falls disproportionately to public, non-profit health systems and to a lesser extent on for-profit hospital systems, as for-profit dialysis providers have generally refused to provide this uncompensated care. These issues are morally complex, time consuming and may place the physician at odds with hospital and dialysis center administrators.

Analysis

Citizens Receiving Uncompensated Care

Uncompensated care is health care that is delivered, but not paid for by either a patient or a third party payer. Most uncompensated care is delivered to the very ill during or after a visit to an emergency room. In 2013, uncompensated care costs totaled $84.9 billion.

Citizens receiving uncompensated care generally fall into two groups: those with annual incomes above 133% of the federal poverty level, and people living at or below the poverty level. Understanding that the definition of affordability may vary, some but not all people in the first category may be able to afford some form of private health insurance. When those individuals get sick, the health care bills are absorbed by providers, taxpayers, and state governments. Costs are shifted to the insured who end up paying higher premiums, or state taxpayers.

As for those living at or below poverty level, 25% of individuals who are eligible for public coverage at little to no cost do not enroll. However, in more than half of the states individuals living in poverty are not eligible for public coverage. While these individuals are not uninsured by choice, they still contribute to the cost-shift or “hidden tax,” which results in higher premiums for the insured.

Over the past decade enactment of the Affordable Care Act (ACA) in 2010 had the largest impact on uncompensated care. On a theoretical level the ACA sought to impact uncompensated care provided in the U.S. by:

- Requiring most U.S. citizens and legal residents to have health insurance;
- Creating state-based American Health Benefit Exchanges through which individuals can purchase coverage, with premium and cost-sharing credits available to individuals/families with income between 133-400% of the federal poverty level (the poverty level was $19,530 for a family of three in 2013);
- Creating separate Exchanges through which small businesses can purchase coverage;
- Requiring employers to pay penalties for employees who receive tax credits for health insurance through an Exchange, with exceptions for small employers.
Imposing new regulations on health plans in the Exchanges and in the individual and small group markets;

- Expanding Medicaid to 133% of the federal poverty level. (Note that not all states took advantage of the Medicaid expansion).

In the context of reducing the number of the uninsured in the U.S. and thus the amount of uncompensated care provided, the ACA has had some success. According to the Center for Disease Control’s 2014 National Health Interview survey on this issue, in the first three months of 2014, among people ages 18-64, 18.4% were uninsured, 17.1% had public health plan coverage and 65.6% had private health insurance coverage; the percentage who were uninsured decreased from 20.4% in 2013 to 18.4% in the first three months of 2014. According to a study in *Health Affairs*, after full ACA implementation in 2016 somewhere between 29 and 31 million people will remain uninsured. Using an estimate of the U.S. population of approximately 310 million people, a rough approximation of the basement level of uninsured citizens would be just under 10%.

The majority of uncompensated care (60%) is provided in hospitals. Community-based providers (including clinics and health centers) and office-based physicians provide the rest, 26% and 14% of uncompensated care, respectively. Kaiser estimates that $53.3 billion was paid to help providers offset uncompensated care costs in 2013. Most of these funds ($32.8 billion) came from the federal government through a variety of programs including Medicaid and Medicare, the Veterans Health Administration, the Indian Health Service, a Community Health Centers block grant, and Ryan White CARE Act. States and localities provided $19.8 billion, and the private sector provided $0.7 billion.

The percentage of people receiving uncompensated care is highest in the South (40%), followed by the West (23%), with individuals from the Northeast and Midwest least likely to receive uncompensated care. Young adults between 19 and 34 have the highest incidence of uncompensated care, while the largest percentage of individuals incurring uncompensated care costs is children.

**Non-Citizens Receiving Uncompensated Care**

The non-citizen population, which is made up of legal permanent residents (defined as aliens who have been legally accorded the privilege of residing permanently in the U.S. as an immigrant in accordance with the immigration laws), and undocumented alien residents (aliens residing in the U.S. who have not entered as immigrants in accordance with the immigration laws). The nation’s non-citizen population has experienced exponential growth in recent decades, and until the financial crisis of 2008 this trend had shown no signs of abating.

The Emergency Medical Treatment and Active Labor Act (EMTALA) enacted in 1986, requires every U.S. hospital emergency department to treat anyone who enters with an “emergency”, which can include conditions ranging from a headache to cardiac arrest. Subsequently, the Personal Responsibility and Work Opportunity Act of 1996 (the Welfare Act) allowed emergency services such as outpatient dialysis for undocumented immigrants to be paid through state Medicaid programs. However, in 2001 the federal government reversed course and mandated that emergency care to undocumented immigrants would only be paid for in emergency departments via EMTALA. The end result of these policy twists and turns is that outpatient dialysis payments were eliminated in most states for this patient population, increasing the level of uncompensated care provided to these patients.
Changes in the scope and focal points of immigration have also impacted issues surrounding care provided to immigrant populations. For states that for many years have sustained high intensity immigration such as Arizona, California, Florida, New Mexico, New York, and Texas, the problem of providing health care to these disadvantaged populations remains serious. In addition, research conducted by the Brookings Institute in 2008 indicates that cities not previously considered to be population centers with high concentrations of immigrants such as Atlanta, Charlotte, Minneapolis-St. Paul, Portland, and Sacramento are now major immigrant destinations. As a result, there is a greater challenge to provide appropriate health care to the legal and non-documented immigrant populations nationwide.

Public Benefits for U.S. Citizens: Current Situation

Public coverage includes Medicaid, which is administered by the states within broad federal guidelines, but financing is shared by the states and the federal government. As a jointly funded cooperative venture between the federal and state governments, Medicaid allows each state, within federally-established national guidelines, to: 1) establish its own eligibility standards; 2) determine the type, amount, duration, and scope of services; 3) set the rate of payment for services; and 4) administer its own program. Medicaid coverage is primarily available to low-income children, parents, pregnant women, people with disabilities, and the elderly. Most non-disabled adults under age 65 who do not have dependent children are not eligible for Medicaid. Due to the Supreme Court ruling in 2012, Medicaid expansion under the ACA was made optional for states. As of late 2014, 27 states plus Washington, DC, had expanded Medicaid under the ACA, and there is some expectation that expansion could occur in up to four additional states.

The number of uninsured non-elderly adults fell by an estimated 8 million between September 2013 and June 2014, representing a drop of 22.3% in the uninsured rate. Further, the uninsured rate for adults in the states that adopted the ACA’s Medicaid expansion dropped 6.1 percentage points since September 2013, compared with a drop of 1.7 percentage points for the non-expansion states.

Inherent characteristics of the Medicaid program do not lend themselves to providing effective health care to marginalized patient populations; this applies to both citizens and non-citizens. As noted above, beyond the issue of expansion the Medicaid program feature that allows each state to determine eligibility, benefits, and reimbursement has resulted in wide variability in the public safety net provided by each of the 50 states. Theoretically, this arrangement is intended to provide each state with the flexibility to provide health care to its neediest patients as deemed appropriate. However, use of such a system has created a fragmented, patchwork program of assistance for the most vulnerable members of society, and hampers efforts to address improving the health care of these individuals on a national level. This situation is only exacerbated in states that have chosen to not expand their Medicaid programs.

Individuals with coverage through a state Health Insurance Exchange Qualified Health Plan (QHP) can remain in that plan when they develop ESRD. Language from the Exchange Final Rule, released in March 2012, states: “We note that neither the proposed nor final rule state that individuals will automatically be terminated from Exchange coverage should they be found eligible for Medicare.” Individuals who choose to remain in their QHP and enroll in Medicare should be aware that they may lose their eligibility for premium subsidies. However, premium subsidies should be maintained until actual Medicare enrollment.
Public Benefits for Non-Citizens: Current Situation

Providing health care to non-citizen patient populations in the U. S. is more complex than for other populations due to a variety of societal and demographic factors, as well as the nature and guidelines of the Medicaid program itself. Among the societal circumstances often complicating care delivery to these individuals are language barriers, poor nutritional status, and fear of deportation. The lack of funding for medications and allied services results in an environment where these patients receive suboptimal care, often for difficult and complex health care problems. Demographically, the non-uniform, nodal distribution of the non-citizen population has disproportionately burdened a relatively small number of states and localities within those states, although the number of states affected by these issues is growing. Additionally, to the extent that the ACA has provided coverage and a path to compensation for care provided to U.S. citizens, this does not apply to undocumented immigrants as they are not eligible for coverage under the ACA.

In 1996, the aforementioned Welfare Act, and the "Illegal Immigration Reform and Immigration Responsibility Act of 1996" (the Immigration Reform Act) substantially altered the landscape by dramatically restricting the access to public benefits by legal and undocumented immigrants, and by raising the admissibility standards for prospective immigrants and increasing the financial responsibility of petitioners for family and employment based immigrants.

The Welfare Act: 1) renders illegal immigrants explicitly ineligible for a broader set of federal public benefit programs, and for state and local public benefit programs; 2) requires states to pass legislation in order to provide benefits to illegal immigrants; and 3) allows states to decide to bar from entry into the Medicaid program qualified aliens (category of aliens including lawful permanent residents, refugees, asylees, and others). The Welfare Act not only bars undocumented immigrants from receiving federal public benefits, but also creates barriers preventing other governmental entities from providing these services. Additionally, among the combined effects of the Welfare Act and the Immigration Reform Act is the reduction of access to the public benefit safety net for legal aliens.

For non-citizen dialysis patients, the cumulative effect of the Medicaid program’s patchwork orientation and the Welfare Act’s barriers to care and eligibility restrictions has created tremendous variability in the level of nephrologic care available from state to state. Access to dialysis through the use of emergency Medicaid (which is still permissible under the Welfare Act) has allowed non-citizen dialysis patients in states such as New York and California to continue treatment, while access to dialysis care for the non-citizen is much more restricted in states such as Texas and Florida. As a result, many non-citizens receive dialysis only in emergency situations as covered by EMTALA. Other states such as Arizona have been sued to ensure that immigrants with ESRD have access to weekly dialysis treatments. These circumstances have created life-threatening double standards of care, not only on a state-by-state basis but also within jurisdictions as some members of at-risk patient groups receive dialysis treatments while others are denied care.

The Medicare Prescription Drug Improvement and Modernization Act (MMA) initially provided $250 million per year for Fiscal Years (FY) 2005-2008 for payments to eligible providers (hospitals, ambulance providers, and physicians) for emergency health services provided to undocumented immigrants and other specified immigrants required by EMTALA. Two-thirds of the funds are divided among all 50 states and the District of Columbia, based on their relative
percentages of undocumented immigrants. One-third is divided among the six states with the largest number of undocumented alien apprehensions. From the respective state allotments, payments are made directly to hospitals, certain physicians and ambulance providers for some or all of the costs of providing emergency health care required under EMTALA and related hospital inpatient, outpatient and ambulance services to eligible individuals. However, free-standing outpatient dialysis facilities are not eligible providers based on the definitions set forth in MMA. As of May 2014, 29 states had exhausted their allocated funds.

Other results from a decrease in federal responsibility for non-citizens include the movement of the financial obligation for these individuals to state and local governments and the health care systems within those areas, and the shift in decision-making authority regarding whether to provide or deny care to individual practitioners and facilities. The fact that the states and the local jurisdictions have little or no input on federal immigration policies calls into question the appropriateness of the federal government’s decision to reduce its duties in this area.

**Ethical Issues Facing Nephrologists and Dialysis Facilities**

While legislative changes limiting health care access and restricting public benefit eligibility for citizens and non-citizens have some degree of an impact on all health care providers, the dilemma nephrologists face is particularly profound. The patient population typically treated by nephrologists is among the sickest and most vulnerable in the nation, and without dialysis, these patients will die. Among the ethical questions facing nephrologists and dialysis facilities are:

- Is it ethical to essentially compel the provider to deny dialysis services to uninsured citizens and non-citizens? Given that one of the few reasons for involuntary discharge from facility is non-payment, providers must determine whether there are legal consequences associated with providing “free” services in an ESRD facility.

- Is it ethical to provide dialysis only (as dictated under emergency Medicaid) and not other services, such as the placement of an AV fistula or management of the catheter needed to help promote safe and optimal health care and achieve positive outcomes?

- Should a provider of dialysis services deny care to an individual based on that person’s ability to pay?

- Does the nephrologist or dialysis facility have a responsibility to report information regarding a patient’s citizenship status to governmental entities?

These issues are not confined to adult ESRD patients. While the pediatric dialysis population is small, there is substantial difficulty in providing ESRD services for children, especially infants and young children, who have no access to health care coverage. Their care is best provided in pediatric dialysis facilities, which are generally part of a hospital, and often a free-standing children's hospital. The cost of dialyzing children is greater than for adults, so even if emergency Medicaid funding is available, it covers a small fraction of the actual cost of a child’s care. In addition, only hemodialysis is covered by emergency Medicaid, thereby denying children access to peritoneal dialysis, which is often a better form of renal replacement therapy for pediatric patients.
A variety of moral and practical rationales exist that legitimately warrant the provision of both dialysis and even the full range of renal-related services to all ESRD patients, regardless of ability to pay or citizenship status. Perhaps the most basic is the humanitarian claim that society is responsible for caring for those who are in need, and that ESRD patients should receive dialysis based on their medical need. The humanitarian value that guides nephrologists and dialysis facility staff to provide life saving therapy to all individuals with ESRD who want it needs to be balanced, however, by the pragmatic concern that some dialysis facilities or hospitals, especially those in low income or high intensity immigration areas, cannot remain fiscally viable if they accept all individuals regardless of their ability to pay. Dialysis facilities or hospitals that jeopardize their financial status by providing uncompensated care do a disservice to their paying patients who have an equal, if not more legitimate, claim to receive dialysis treatments and other health care services. Prudence and justice require that nephrologists, hospitals, ancillary care providers and dialysis facilities do as much as they can for fiscally disadvantaged patients and that they be adequately compensated for this care so they preserve their ability to provide quality dialysis care for their other patients.

On a more pragmatic level, it is likely that providing the standard level of ESRD care to both non-paying citizens and non-citizens will prove to be a prudent decision longitudinally. Providing dialysis and possibly other renal-related services to these individuals may be a better use of increasingly scarce resources as, through improved health outcomes, these patients may be able to return to work sooner and be able to better care for their dependents. Further, optimal health maintenance for non-paying citizens and non-citizens with renal failure will invariably reduce the need for costlier emergency room care, and the abuse of critical care resources such as hospitalizations and unnecessary invasive procedures.
Principles

1. All health care professionals and health care systems have an ethical obligation to treat the sick.

2. The federal government has the ethical and fiscal responsibility to provide care for patients within the U.S. borders.

3. The financial burden of ESRD patient care should fall not only on those states that have the highest number of uninsured citizens or non-citizens, but should be a national responsibility.

4. Due to the unique nature of ESRD, all citizens and non-citizens with ESRD should be eligible for emergency federal funding if they do not have insurance or resources to pay for renal-related care.

5. Nephrologists should not be expected to act as agents for the Immigration and Naturalization Customs Enforcement Agency Service and therefore, should not be expected to report undocumented non-citizens because of patient confidentiality and the fiduciary nature of the patient-physician relationship.
References


